FULL COUNCIL MEETING MINUTES June 17, 2019 - 1:00 PM

STATE COUNCIL FOR PERSONS WTH DISABILITIES

Felton-Farmington Room, DelDOT Administration Building, Dover (CART/ASL Provided)

PRESENT

Terri Hancharick, Vice-Chair; Samara Kaminski, DDDS (for Leslie Hailey); Susan Campbell, DHSS/DMS/Birth to Three; Anthony Carter, JEVS; Karen DiNardo, State Rehabilitation Council; Susannah Eaton-Ryan, The Arc of Delaware; Kristy Handley, BIAD; Elisha Jenkins, DVI; Karen McGloughlin, DHSS/DPH; Daniese McMullin-Powell, Advocate; Loretta Sarro, DVR-ODHH; Lloyd Schmitz, Council on the Blind; Belinda Strickland, DART; Laura Waterland, CLASI/DLP; Danielle Gumbs, DSAMH (for Elizabeth Romero); Sybil Baker, GACEC (for Wendy Strauss); Laura Waterland, CLASI/DLP; Despina Wilson, IRI, Inc.; Kyle Hodges, Staff; Amber Rivard, Support Staff; and Jo Singles, Support Staff.

GUESTS

Victoria Counihan, DOJ/AG Bill Powell

Interpreters: Caroline Greene/Peg Stewart

CALL TO ORDER

Terri called the meeting to order at 1:13 pm. Introductions were made.

ADDITION OR DELETIONS TO THE AGENDA

- Committee Reports - Initiatives - DHH Community

APPROVAL OF MINUTES

Loretta made a motion to approve the May 20, 2019 meeting minutes as submitted. Karen McGloughlin seconded the motion. The motion was carried with Daniese abstaining and no one opposing.

BUSINESS

Updates from DDDS

This was not addressed due to the appropriate DDDS representative not being able to attend.

Follow-Up Discussion re: Group Homes for Individuals who are Deaf/Hard of Hearing

Kyle spoke about the presentation at last month's presentation regarding Group Homes for Individuals who are Deaf/Hard of Hearing. A major problem is that deaf clients in the DDDS system are not able to communicate while living in group homes. Kyle stated that he hoped for discussion and for the Council to take a stand on how to move forward. He commented that ADA talks about reasonable accommodations. Laura commented that, at a minimum, we need to take a position that DDDS needs to do a better job of developing services for people who are deaf in the community.

Kyle commented that this topic was discussed at the Executive Committee earlier today. Members of the Executive Committee said that, if the issue is about communication in group homes, it should be with reasonable accommodations. If people live in group homes with three to four individuals, abide by the Community Rule, and have reasonable accommodations for communication, that is something we could support. Susannah spoke of having heard conflicting information at the last meeting, but brought the information back to her office. She does not know where the Arc or the community as a whole stands on this issue.

Karen McGloughlin suggested a multi-layered approach. She stated that much of this is on a one-on-one service level and asked what is required by law? She added that we can also look at system changes and review the timeline differently. Karen asked how can staff be trained in ASL to fulfill these jobs and can this be required as a standard in the future so that we have more people that are able to perform these functions. She suggested that we can encourage schools to teach ASL as a second language so everyone has an awareness at a minimal.

Loretta spoke about her experience, including being a student at DSD. She commented that DSD has students who are deaf only, but some have another disability. Once a student graduates, the services do not follow. Some students have no or limited communication. It also depends on the individual's family background. Gallaudet University (Washington, DC) and the National Technical Institute for the Deaf at the Rochester Institute of Technology (New York) have social work majors for individuals who are deaf. Graduates from Gallaudet have reached out to her looking for positions in Delaware. Loretta stated that many individuals are isolated in their homes, although they may have part-time jobs due to receiving Social Security. Graduates of Gallaudet may be licensed in DC, but not in Delaware. Loretta asked why these social workers cannot be hired and then assist them to acquire their license in Delaware.

Daniese stated that this Council's mission and goal should be for 100 percent inclusive community. It is not supportive to support people living in silos or being segregated. Group homes (according to the Community Rule) should be fully accessible to those who are deaf and/or blind and be accomplished by reasonable accommodations. Daniese commented that she feels uncomfortable not being deaf and taking part in this conversation. She added that when there are many people with many different views those should be included in this conversation. Despina commented that what she got out of the last meeting was that this is a language barrier, and deaf people need to be somewhere where people speak their language. She added that she also understands what Daniese is saying and that we are all working to have as much integration as possible. Despina said that, if this is coming from the community itself, this is a need--the culture is more than providing interpreters. Terri noted that the data in the presentation was from a 2003 study and the information on social integration on students mainstreamed was from 2007. She hoped this was not true today.

Karen suggested having a subcommittee narrow the focus of exactly what the community would like us to do since the last meeting was very broad. She said that we need some clarity and a subcommittee or task force could work with the community representatives to narrow the focus. Loretta agreed that the presentation was not clear. She understands their point, but we need to know how many people need communication access in group homes. She also spoke about her personal experiences on a daily basis. She makes her way through with success, but some people cannot, and these people really need access to ASL. She added that she was mainstreamed for math classes for three years. Terri stated that we support three to four individuals in a group home or apartment, receiving the supports they need. Despina commented that the best group to give direction is the group itself. She asked if we have statistics or is it necessary to do statewide gatherings on key players in the deaf community. She added that Linda

Heller's group (HLADE) would have information. Despina commented that there is a level of isolation, we need to find the level of need and how to get to that core population that needs the service, and what does that service look like. Sybil asked for clarification about what we are supposed to be doing—research or have a discussion and come up with a decision based on what this group is asking the Council to support and what the Council supports. Kyle clarified that it would be the latter. He added that DDDS reported 19 individuals who are deaf and hard of hearing in group home settings. The group presenting was aware of 30 people. Kyle added that they want guidance from the Council and how to move this forward. Council needs to, at least, provide a position statement, which would allow us to continue working with them to determine the best route. Lloyd added that we need to say that we do not support a separate community or village. He added that if people want a village in the private sector, that is a choice they can make. However, group homes receive government funding.

Kyle read the following statement: SCPD supports group homes for people with I/DD that are deaf and hard of hearing if in compliance with the home and community based final rule and with reasonable accommodations for access to communications. The SCPD will work with the deaf and hard of hearing community and DDDS to build an infrastructure and system that would promote total inclusion in the community for people who are deaf and hard of hearing. SCPD does not support large communities that house one particular population.

Sybil made a motion to support the statement listed above. Karen McGloughlin seconded the motion. The motion was carried with Loretta abstaining and no one opposing.

Committee Reports

Employment First Oversight Commission – Kyle reported that EFOC has received all the baseline data that was requested by relevant State agencies. This information will be put into an Annual Report. Also, draft legislation was submitted to Representative Heffernan and Senator McDowell to revamp the Commission by adding DSAMH and DVI as members and a few other changes. Lloyd asked if the term limits were going to be revised. Kyle stated that section would be revised by taking out term limits to make it easier to keep members and keep the Commission functional.

Brain Injury Committee - Kyle stated that a bill had been introduced last week, which will allow SCPD to access the DHIN (Delaware Healthy Information Network) claims database so that statistics on the number of TBIs in Delaware can be retrieved. He thanked Karen McGloughlin for her leadership as Chairperson on the subcommittee that made this happen. This effort will be cost effective. Karen added that there are four State agencies that currently have access to this information. She stated that this is a huge step forward and gives access without expense. Everyone applauded Karen. Kristy commented that this is a big step in gathering information and being able to provide services to people with brain injuries. She also hopes that those inputting the data will enter the information we need. Kyle added that this might leverage federal funding opportunities for Delaware. Because data was lacking in the past, we were not able to get federal grants.

Policy & Law Committee -

Kyle referenced a Legislative Update (handout), which had been given to the Center for Disabilities Studies Advisory Committee. He reviewed the following legislation:

- HB 164 would codify the DDC. DDC had not been contacted for their input. This bill is on hold and the sponsor of the proposed legislation has indicated a meeting with DDC will take place before January.
- SB 154 establishes the Quality Improvement Advisory Council to promote collaboration and problem solving with stakeholders in the system of care administered by DDDS. The legislation states that SCPD recommends four people for the Advisory Council. That is positive. The legislation will be heard in the Sunset Committee on Wednesday, June 19th. However, he noted that concerns have been raised about this legislation, one of which is that the affected agencies were not given prior notice.
- HB 140 End of Life Options Representative Baumbach attended the Policy & Law Committee on May 20th. He distributed a memorandum from Debbie Gottschalk where the following question was posed: *Does a Delaware resident who is terminally ill and in the last 6 months of life meet the definition of being disabled so that SCPD has standing to offer an opinion on HB 140?* In a nutshell, SCPD responded that many individuals with terminal illness would meet the definition of disability and HB 140 actually has the potential to impact a disproportionate number of individuals who have a disabling condition. In addition, SCPD is well within its scope and statutory mandate to address any issue that has the potential to affect the lives of Delaware's citizens with disabilities, including HB 140. Kyle will share the referenced memorandum and SCPD's response.

Kyle stated that funding was approved for the following legislation:

- \$1,277,000 for DMMA Dental Coverage for Adult Medicaid Recipients
- \$1,800,000 for DSAAPD to reduce the PAS (Personal Attendant Services) waiting list
- \$4,200,000 for direct support professionals (DSP) wage increase

Kyle thanked Terri for her efforts. He also thanked DSAAPD for the data that we presented to legislators that showed the need. The current PAS waiting list (as of April 22) is 247, with 203 being high priority, with the rest being medium or low priority. The cost to reduce this waiting list would be \$3M.

Terri spoke about SB 163, which creates a Committee to study separating DHSS into two Departments-one Department would focus on advocacy and services to people with disabilities and Medicaid, and the other would focus on Health Care and Policy. The Committee to study this would include the following:

- (1) A Senator from the majority caucus, appointed by the President Pro Tempore, who shall serve as Chair.
- (2) The Secretary of the Department of Health and Social Services, who shall serve as Vice-Chair.
- (3) A Senator from the minority caucus, appointed by the President Pro Tempore of the Senate.
- (4) A Representative from the majority caucus, appointed by the Speaker of the House of Representatives.
- (5) A Representative from the minority caucus, appointed by the Speaker of the House of Representatives.
- (6) The Director of the Office of Management and Budget.
- (7) The Controller General.
- (8) A designee of the State Council for Persons with Disabilities (SCPD).
- (9) A designee of the Delaware Healthcare Association.

- (10) One member of the public who has expertise in the delivery of health and social services to vulnerable populations, appointed by the President Pro Tempore of the Senate.
- (11) One member of the public who has expertise in the delivery of health and social services to vulnerable populations, appointed by the Speaker of the House of Representatives.

Terri noted that implementation would not happen before 2021. The proposed legislation will be sent to Council members. Kyle noted that DHSS has not been revamped since its establishment in 1970.

Lloyd asked if the Governor's Commission on Building Access to Community Based Services has been meeting. Kyle commented that they have met once since December and it was a small turnout. He does not know of any future meeting dates.

<u>Initiatives – Deaf & Hard of Hearing</u>

Kyle spoke about a meeting with a group called "Deaf Outreach," which is a grassroots organization. Loretta is a member. This group wants to update the Visor Card that a deaf person can put on their dashboard saying that they are hearing impaired if pulled over by the police. The Visor Card is now ten years old. Currently, there is a sticker that can also be placed on the person's Driver's License that says they are "hearing impaired". This group would rather have a notation on their license similar for those who wear glasses. Also, an identifiable marker could be put on the license plate would be useful when the police are checking the license plate in the computer system. Kyle contacted Secretary Coupe to obtain their guidance and there is a preliminary meeting next Monday to discuss this issue. Gail Garner (from Deaf Outreach) will also be attending. Loretta commented that the meeting with Deaf Outreach was successful and productive. She has researched other states and has chosen some to review to update our Visor Card. She added that ideas would be presented to the deaf community for their feedback.

Kyle spoke about the creation of a Registry of Interpreters, which has been a project of the Deaf & Hard of Hearing Workgroup. A meeting will be held with DVR representatives, including their Attorney General, to review draft legislation. Final recommendations will be made by the Deaf & Hard of Hearing Committee after this meeting.

ANNOUNCEMENTS

Kyle spoke about the update from DDDS and the new implementation of being Medicaid eligible for the Lifespan Waiver for services. He asked Samara to take a request to DDDS that we want the number of people who will be losing services and want to know the reason they are losing services. Susannah commented that the last communication with Stacy Watkins was that there was not any news. She added that an explanation was given at a provider meeting that no one will be dropped if he or she shows a good faith effort to obtain Medicaid. Susannah stated that there is an evening meeting at Fox Run on June 25th with Columbus (the agency that provides case management) and DDDS to assist clients in filling out applications. She has not received information since May on the status of their clients and many individuals from Bank of America are on their roster.

Daniese announced that the Disability Integration Act (federal) currently has 224 co-sponsors (HR555 and S117). The legislation is currently in the House Energy Commerce and Finance Committees. This legislation has a good chance of passing in the House by the anniversary of the ADA and then moving onto the Senate for passage next year.

PUBLIC COMMENT

None

ADJOURNMENT

Terri thanked everyone for attending and participating. Lloyd made a motion to adjourn the meeting. The meeting adjourned at 2:40 pm.

Respectfully submitted,

Jo Singles Administrative Specialist

SCPD/minjune19